

## 2018 Current Fiscal Year Report: Center for Inherited Disease Research

### Access Committee

Report Run Date: 06/05/2019 09:17:34 AM

#### 1. Department or Agency

Department of Health and Human Services

#### 2. Fiscal Year

2018

#### 3. Committee or Subcommittee

Center for Inherited Disease Research Access Committee

#### 3b. GSA Committee No.

5167

#### 4. Is this New During Fiscal Year?

No

#### 5. Current Charter

04/30/1997

#### 6. Expected Renewal Date

#### 7. Expected Term Date

#### 8a. Was Terminated During Fiscal Year?

No

#### 8b. Specific Termination Authority

#### 8c. Actual Term Date

#### 9. Agency Recommendation for Next Fiscal Year

Continue

#### 10a. Legislation Req to Terminate?

Not Applicable

#### 10b. Legislation Pending?

Not Applicable

#### 11. Establishment Authority

Authorized by Law

#### 12. Specific Establishment Authority

42 U.S.C. 282(b)(16)

#### 13. Effective Date

11/20/1985

#### 14. Committee Type

Continuing

#### 14c. Presidential?

No

#### 15. Description of Committee

Other Committee

#### 16a. Total Number of Reports

No Reports for this Fiscal Year

#### 17a. Open Meetings and Dates 0 17b. Closed Meetings and Dates 5 17c. Partially Closed Meetings and Dates 0 17d. Total Meetings and Dates 5

Purpose	Start	End
NIH Peer Review	11/09/2017	- 11/09/2017
NIH Peer Review	01/12/2018	- 01/12/2018
NIH Peer Review	05/04/2018	- 05/04/2018
NIH Peer Review	07/20/2018	- 07/20/2018
NIH Peer Review	09/07/2018	- 09/07/2018

#### Number of Committee Meetings Listed: 5

	Current FY	Next FY
18a(1). Personnel Pmts to Non-Federal Members	\$6,000.00	\$6,000.00
18a(2). Personnel Pmts to Federal Members	\$0.00	\$0.00
18a(3). Personnel Pmts to Federal Staff	\$83,988.00	\$85,584.00
18a(4). Personnel Pmts to Non-Member Consultants	\$0.00	\$0.00
18b(1). Travel and Per Diem to Non-Federal Members	\$9,080.00	\$9,147.00
18b(2). Travel and Per Diem to Federal Members	\$0.00	\$0.00
18b(3). Travel and Per Diem to Federal Staff	\$0.00	\$0.00

<b>18b(4). Travel and Per Diem to Non-member Consultants</b>	\$0.00	\$0.00
<b>18c. Other(rents,user charges, graphics, printing, mail, etc.)</b>	\$76.00	\$77.00
<b>18d. Total</b>	\$99,144.00	\$100,808.00
<b>19. Federal Staff Support Years (FTE)</b>	0.40	0.40

**20a. How does the Committee accomplish its purpose?**

This committee is composed entirely of recognized biomedical and/or behavioral research authorities who represent the forefront of research and technical knowledge in the mapping of loci responsible for the genetic contribution to common disorders in humans, including, but not limited to, cardiovascular and pulmonary disease, cancer, psychiatric disorders, diabetes, and autoimmune diseases. The Center for Inherited Disease Research (CIDR) is a consortium of 10 Institutes. The National Human Genome Research Institute is the lead agency for the consortium which manages CIDR through a Board of Governors representing each of the 14 Institutes. CIDR advises the Director, NIH, and the Board of Governors on the scientific and technical merit of applications seeking to use the genotyping and genetic analysis capabilities of CIDR. During this reporting period the committee approved 7 applications requesting access to the CIDR facility.

**20b. How does the Committee balance its membership?**

The members of this committee are recognized authorities knowledgeable in the various disciplines and fields of human genetics, quantitative genetics, linkage and segregation analysis, and genotyping technology.

**20c. How frequent and relevant are the Committee Meetings?**

The Center for Inherited Disease Research Access Committee held five meetings during this reporting period.

**20d. Why can't the advice or information this committee provides be obtained elsewhere?**

This committee is composed entirely of recognized biomedical and/or behavioral research authorities who represent the forefront of research and technical knowledge and who provide review of highly scientific and technical research applications requesting access to the CIDR facility. These evaluations and recommendations cannot be obtained from other sources because the specialized, complex nature of the applications requires a unique balance and breadth of expertise not available on the NIH staff or from established sources.

**20e. Why is it necessary to close and/or partially closed committee meetings?**

The meetings of the Center for Inherited Disease Research Access Committee were

closed to the public for the review of applications. Sections 552b(c)(4) and 552b(c)(6) of the Government in the Sunshine Act permit the closing of meetings where discussion could reveal confidential trade secrets or commercial property such as patentable material and personal information, the disclosure of which would constitute a clearly unwarranted invasion of personal privacy.

## 21. Remarks

Committee Function: Other - Review of requests for access to the Center for Inherited Disease Research. Reports: This committee did not produce any public reports during the fiscal year. The DFO and Decision Maker are the same person, Barbara Thomas, Scientific Review Officer, NHGRI, based on the assignment of duties in this Institute. URL: This committee does not have a website.

## Designated Federal Officer

### BARBARA THOMAS SCIENTIFIC REVIEW OFFICER

Committee Members	Start	End	Occupation	Member Designation
BRZUSTOWICZ, LINDA	08/24/2017	06/30/2021	DISTINGUISHED PROFESSOR	Peer Review Consultant Member
EPSTEIN, MICHAEL	07/01/2015	06/30/2019	PROFESSOR	Peer Review Consultant Member
FINGERLIN, TASHA	07/18/2016	06/30/2020	ASSOCIATE PROFESSOR	Peer Review Consultant Member
GEJMAN, PABLO	07/01/2016	06/30/2020	DR. LOUIS W. SAUER CHAIR OF RESEARCH	Peer Review Consultant Member
KOOPERBERG, CHARLES	08/23/2017	06/30/2021	FULL MEMBER AND PROGRAM HEAD	Peer Review Consultant Member
KRAFT, PETER	07/01/2014	06/30/2018	PROFESSOR	Peer Review Consultant Member
KWOK, PUI-YAN	07/01/2015	06/30/2019	HENRY BACHRACH DISTINGUISHED PROFESSOR	Peer Review Consultant Member
LUNETTA, KATHRYN	08/23/2017	06/30/2021	PROFESSOR	Peer Review Consultant Member
MARAZITA, MARY	07/06/2016	06/30/2020	PROFESSOR AND VICE CHAIR	Peer Review Consultant Member
MITCHELL, BRAXTON	08/24/2017	06/30/2019	PROFESSOR	Peer Review Consultant Member
MOHLKE, KAREN	07/01/2018	06/30/2022	PROFESSOR	Peer Review Consultant Member
SCHAID, DANIEL	08/23/2017	06/30/2021	PROFESOR	Peer Review Consultant Member

**Number of Committee Members Listed: 12**

## Narrative Description

The goal of NIH research is to acquire new knowledge to help prevent, detect, diagnose, and treat disease and disability, from the rarest genetic disorder to the common cold. The NIH mission is to uncover new knowledge that will lead to better health for everyone. NIH

works toward that mission by supporting the research of non-Federal scientists in universities, medical schools, hospitals, and research institutions throughout the country and abroad. Section 492 of the PHS Act states that The Secretary ...shall by regulation require appropriate technical and scientific peer review of -(A) applications...; and (B) biomedical and behavioral research and development contracts...

**What are the most significant program outcomes associated with this committee?**

Checked if Applies

- |   |                                     |
|---|-------------------------------------|
| Improvements to health or safety                  | <input type="checkbox"/>            |
| Trust in government                               | <input type="checkbox"/>            |
| Major policy changes                              | <input type="checkbox"/>            |
| Advance in scientific research                    | <input checked="" type="checkbox"/> |
| Effective grant making                            | <input type="checkbox"/>            |
| Improved service delivery                         | <input type="checkbox"/>            |
| Increased customer satisfaction                   | <input type="checkbox"/>            |
| Implementation of laws or regulatory requirements | <input type="checkbox"/>            |
| Other   | <input type="checkbox"/>            |

**Outcome Comments**

NA

**What are the cost savings associated with this committee?**

Checked if Applies

- |                            |                                     |
|----------------------------|-------------------------------------|
| None                       | <input type="checkbox"/>            |
| Unable to Determine        | <input checked="" type="checkbox"/> |
| Under \$100,000            | <input type="checkbox"/>            |
| \$100,000 - \$500,000      | <input type="checkbox"/>            |
| \$500,001 - \$1,000,000    | <input type="checkbox"/>            |
| \$1,000,001 - \$5,000,000  | <input type="checkbox"/>            |
| \$5,000,001 - \$10,000,000 | <input type="checkbox"/>            |
| Over \$10,000,000          | <input type="checkbox"/>            |
| Cost Savings Other         | <input type="checkbox"/>            |

**Cost Savings Comments**

NIH supported basic and clinical research accomplishments often take many years to unfold into new diagnostic tests and new ways to treat and prevent diseases.

**What is the approximate Number of recommendations produced by this committee for the life of the committee?**

**Number of Recommendations Comments**

346 projects were recommended for access consideration to CIDR including the 7 projects considered in FY2018.

**What is the approximate Percentage of these recommendations that have been or will be Fully implemented by the agency?**

0%

**% of Recommendations Fully Implemented Comments**

N/A

**What is the approximate Percentage of these recommendations that have been or will be Partially implemented by the agency?**

0%

**% of Recommendations Partially Implemented Comments**

N/A

**Does the agency provide the committee with feedback regarding actions taken to implement recommendations or advice offered?**

Yes ☒ No ☐ Not Applicable ☐

**Agency Feedback Comments**

The agency provides oral and written reports.

**What other actions has the agency taken as a result of the committee's advice or recommendation?**

Checked if Applies

Reorganized Priorities	<input type="checkbox"/>
Reallocated resources	<input type="checkbox"/>
Issued new regulation	<input type="checkbox"/>
Proposed legislation	<input type="checkbox"/>
Approved grants or other payments	<input type="checkbox"/>
Other	<input checked="" type="checkbox"/>

**Action Comments**

After considering this committees recommendations,successful applicants were granted

access to to the genotyping and genetic analysis capabilities of the Center for Interited Disease Research facility.

**Is the Committee engaged in the review of applications for grants?**

No

**Grant Review Comments**

Successful applicants are provided with access to the genotyping and genetic analysis capabilities of CIDR rather than funds. The access to CIDR is paid by the Institute or Center that funded the original grant application.

**How is access provided to the information for the Committee's documentation?**

Checked if Applies

Contact DFO	<input checked="" type="checkbox"/>
Online Agency Web Site	<input checked="" type="checkbox"/>
Online Committee Web Site	<input type="checkbox"/>
Online GSA FACA Web Site	<input checked="" type="checkbox"/>
Publications	<input type="checkbox"/>
Other	<input type="checkbox"/>

**Access Comments**

IC Committee Management Officer 240-669-5201